This work was commissioned by the Office of London Clinical Commissioning Groups, the mental health support charity Certitude and South London and Maudsley NHS Foundation Trust in order to better understand the experiences of people who have psychosis. Specifically, they sought to understand the experiences of people who use Early Intervention in Psychosis services in three south London boroughs: Lambeth, Southwark and Lewisham, to support the development of those services. Later the study was opened to people using Early Intervention in Psychosis services in Barnet, Enfield and Haringey.

The McPin Foundation were commissioned to conduct an in-depth qualitative study exploring the experiences of people who have used local Early Intervention in Psychosis services and the experiences of their carers. We called the project *My Story: Our Future*, a title that came out of discussions with our team and the project steering group.

Over the last 15 years, the NHS has developed services for people between the ages of 14 and 35 who are experiencing their first episode of psychosis (Pinfold et al. 2007). These Early Intervention in Psychosis services focus on the early detection and treatment of symptoms. Studies have shown the services lead to better long-term clinical outcomes for service users compared with generic community or inpatient mental health care (Singh, 2010) and they now form an integral part of the community mental health offering in England.

However, few in-depth qualitative studies have explored the experiences of people with psychosis. Much of the existing work is restricted to people’s experiences of using psychosis services (Rhodes, 2015; Sebergesen, 2014; Tindall et al., 2015; van Schalkwyk, 2015) or their pathways into care (Jansen et al., 2015). There is less published research that explores the broader context of people’s lives and the situations and events that may have contributed to people who use services needing them.
in the first place, although exceptions to this includes work by the Exploring Psychosis Together group (2012) and Thornhill, et al. (2016).

With this in mind, My Story: Our Future adopted an approach that deliberately sought to look beyond people’s experiences as a ‘service user’ or ‘carer’. We set out to hear people’s life stories to see if they could help us identify and understand important events or experiences which have had an impact on their mental health.

People seeking help from mental health services are constantly asked to tell their stories to psychiatric professionals. However, this is usually within the restrictions of a psychiatric assessment. They are rarely given the space to tell their story on their own terms and as Morgan notes in Values and Ethics in Mental Health: An exploration for practice, “Little space is to be found here for engaging with personal meaning making...”. Telling our stories is one way in which we “make sense of our lives, our identities and our worlds” (Morgan et al, 2016).

To do this work, we looked to techniques used in the collection of oral histories. Oral history is a method of gathering, preserving and interpreting the voices, memories, feelings and attitudes of people and communities (Lummis, 1987). Oral histories enable people and communities to narrate their experiences in their own words, voices that might not otherwise be heard and are often marginalised or invisible within mainstream history. People and communities are enabled to provide first-hand accounts of the past that can enhance, or even challenge, dominant historical accounts (Frisch, 1990).

We were drawn to this approach as a way of complementing the wealth of quantitative literature about early intervention services and the demographic profiles of the people using them. Our aim was to listen to the life stories of people who use Early Intervention in Psychosis services, or care for someone who does, to understand their experiences of managing psychosis within and beyond formal services.

We wanted to give people a voice to tell their own stories and give their own accounts of psychosis within the context of their lives. We have learnt a lot from doing this project as a team and took a lot longer over the work than planned to ensure that we worked with people’s stories carefully, consistently and thoughtfully throughout.

**WHY DO OUR STUDY THIS WAY?**

**Dolly’s perspective**

> As a service user, I accessed my patient notes for a book I was writing. It was quite a shocking, dehumanising experience. All I could see was the pathology of me or the observable data of unobservable worlds.

It did not show the truth of me. You do not see the Dollyness of Dolly in my psychiatric notes. You do not see the Garyness of Gary in his. This is what this study aims to do: to decipher the human being behind the patient notes, to see their life beyond the consulting room, the hospital, the community mental health team.
Before we begin to introduce peoples’ stories, it is important that we also ‘tell the story’ of this research project and particularly of the survivor researchers who conducted it.

We were initially approached by the charity Certitude in July 2015 with a brief to gather the stories of people who had been using Early Intervention in Psychosis services in Lambeth, Lewisham and Southwark.

During those early discussions we decided that it would be essential to recruit researchers who had lived in the local area and who had themselves experienced psychosis and used mental health services.

We were successful in recruiting three researchers, two of whom, Gary Coyle and Dolly Sen, remained with the project from start to finish. We asked them to select their preferred term to describe their role and they chose ‘survivor researcher’, which we use throughout.

Throughout this report you will encounter writing from Gary and Dolly in which they reflect on what they heard from the people who participated in this study and how the stories related to their own experiences of psychosis and encounters with services.

Dolly, Gary and a third researcher who wishes to remain anonymous worked together to develop My Story: Our Future. It was coordinated by two members of staff from the McPin Foundation.

Initially, Agnes Hann worked with the survivor researchers to decide how the study would run, design the study protocol and study materials, and to gain ethical approval. She also coordinated the recruitment of participants in the early stages and conducted interviews with the survivor researchers.

The coordination was later passed to Rose Thompson, who co-led many of the interviews and coordinated the analysis and study write up. During this time, one of the original survivor researchers left the study to pursue other opportunities.

Our team was completed by Alison Faulkner, a survivor researcher, who has experience of using mental health services but not of psychosis. Alison worked with us in an advisory capacity throughout and worked with us to analyse the life stories and write sections of this report.
WHY GET INVOLVED?

Alison’s perspective

I was attracted to this project because of its focus on hearing people’s stories. I have been a survivor researcher for many years, having had my own experience of using mental health services, and worked on many different research projects and consultations.

Rarely do we have the time in research to really listen to people’s stories. In mental health services, our story often becomes obscured by professionals who need us to fit into their model of what mental distress represents.

I believe that it is through telling our own stories that we come to understand our mental distress within the context in which we are living and have been living and will go on living.

It is an active process and a way we can help and support each other to understand mental distress – if we are allowed the space to tell our stories, we can begin to open up the space for understanding.

As one of our participants said: ‘It is a very special experience which people go through and they need more support for it and be able to talk to more and more people who have also gone through that [...]’.

You still need that safe environment where you feel accepted and not being laughed at and understood.

GATHERING LIFE STORIES

In the early stages of the study, Agnes undertook training in a research method called ‘Oral History interviewing’. This is a kind of interview that historians use to collect the stories of people who were alive during important times in recent history.

It is designed to allow people to tell their experiences of complex events in their own words. Agnes incorporated learning from this type of interviewing into our study protocol.

She also trained the survivor researchers in the approach and together they developed a plan for how they would carry out the interviews with the ‘storytellers’ – as we now began to think of our participants.

The researchers created a set of visual resources including visual life maps and timelines that storytellers could use (see Tree of Life diagram overleaf). These resources would allow storytellers time to think about what parts of their story they would like to tell and what parts they would like to keep private.
Mapping resource: Tree of Life (adapted from Ncube, 2006)
Difficulties with recruitment

Rose’s reflection

“I have been working in research for about 10 years and I actually found this study quite difficult to recruit to. I think we spoke to about 4 people for every person who decided to take part. I think there are a number of reasons for this.

The most significant obstacle was the kind of Research and Development Approval we were able to get (the permission we needed to begin). We received something called Patient Identification Centre approval, which meant that while we could identify potential participants through services, we were not able to conduct research activities on NHS Trust premises. This meant that we were unable to spend much time in services and so did not become familiar to the staff or the people using the services.

Early Intervention in Psychosis services are very busy, often pressured places, and the clinical staff may not have had much time to talk to the people they worked with about our study. If we had been visible, we would have been able to develop more trusting relationships and be on hand to explain more about the study. However, I also think that this was not the right study for some people. Many people were still making sense of what had happened to them and were not at the right point in that journey to be able to tell their story.

If we were to conduct a similar study again, it may be better to try to recruit people who are approaching discharge or have recently been discharged.”

Dolly’s perspective

“I found the recruitment so frustrating. We couldn’t relate to people as fellow human beings and had to go through hoops and procedures and trust overworked care coordinators to do their part.

It felt like an ‘othering’ process too, which I didn’t feel comfortable with, causing a separation between myself and the participants that wasn’t there when we started.”
INVITING PEOPLE TO TAKE PART IN THE STUDY

We found our storytellers by asking staff at Early Intervention in Psychosis services to advertise *My Story: Our Future* and to talk to people about it. When staff spoke to potential storytellers they would explain a little bit about what would happen. Potential storytellers could then either contact us directly or they could pass their contact details to us through a member of staff at their service.

We would then meet with people to talk to them about the study. We did this so that potential storytellers could connect with us and find out about what we were like as a research team. They could also ask questions about what would happen during the sessions with us. People then decided whether they wanted to take part or not; we encouraged them to take time in making this decision.

Relatives and people who cared for someone using Early Intervention in Psychosis services were approached through carers’ groups. The survivor researchers attended these groups and explained what the study was about. People who were interested then spoke to them during the group about the study, and if they were happy to take part, gave us their contact details. We then contacted them to arrange an interview.

By the end of the study, we had heard the stories of people from Enfield who were or had been under the care of Barnet, Enfield & Haringey Mental Health NHS Trust (BEH), and from Lambeth, Lewisham and Southwark, who were or had been under the care of South London and Maudsley NHS Foundation Trust (SLaM).

WHY DID THE STORYTELLERS TAKE PART?

Gary and Dolly in conversation

**Gary:** I think the majority of them just wanted to be heard. They’ve been dismissed so many times by the services and talked down to, they wanted to get their views across. Some of them hoped to make services better for others in the future by sharing what they have with us.

**Dolly:** That’s the impression I got as well, that they were just waiting to tell their story and they had the chance to do it. But we tried to think how many people have not had their chance to tell their story. Maybe that’s one way services can improve – by giving people that chance. I mean one guy said that he wants people not to go through what he went through and that the services will treat others in a better way. I hope the project will have that impact and it will honour that intention, I think.
INTERVIEWERS AND STORYTELLERS

Storytellers were usually interviewed by two or more researchers. In most cases, one or more of the survivor researchers, Dolly or Gary, would be paired with one of the study coordinators, Agnes or Rose, to do the interview. Dolly and Gary both have experience of psychosis and had used mental health services. Dolly had some experience of interviewing before, whilst Gary was relatively new to research when he joined our team.

When Dolly or Gary were in the room, the storytellers knew that they were talking to someone who had been through a similar experience to them and who knew a bit about how it feels to use mental health services.

We hoped that this would enable storytellers to feel more at ease with the process and more comfortable when telling their story, as at least one of the interviewers would have an ‘insider’ understanding of what they had been through.

In contrast, neither Agnes nor Rose had any experience of psychosis or of using services for psychosis but both had a lot of experience of conducting interviews. This meant that they could offer support to Gary and Dolly during the interviews and take the lead in asking questions as required.

MAPPING STORIES

We conducted interviews in a number of stages. Once people had agreed to take part, we invited them to come to the McPin Foundation to take part in a mapping meeting. Storytellers were shown the visual resources we had developed and were able to choose between the different options.

The idea was that they would be able to spend some time thinking about how they wanted to tell their story and potentially to create a visual ‘map’ to use through the interviews.

While we spent some time with all interviewees going through this mapping process, some were comfortable simply beginning their story. For these storytellers, it was easier to tell their story in a free-flowing conversation than it was to try to pin down their story using the visual resources. Others brought their own visual resources with them.

One storyteller had made a film based on his experiences and brought his storyboard\(^1\) for us to see. A second person asked if we were able to bring a keyboard to the interview, which we did, so that she could play some music for us. A third person brought documents and certificates for us to look at while he was talking.

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1. A storyboard is a graphic display with illustrations or images in sequence for the purpose of presenting the visual story of a film or animation.
MAPPING RESOURCE: LIFE COURSE MAP

THE BEGINNING: OUR STARTING POINTS

CHILDHOOD

MY STORY

OUR FUTURE

WHERE I AM NOW

YOUNG ADULT

FIRST DIAGNOSIS

ADULT
RECORDING STORIES

Once we had discussed mapping with the participants, we invited them to begin a recorded interview. For some, this meant beginning to tell their story while still in the process of looking at the mapping materials, as thoughts naturally occurred to them.

For others, it meant having a careful discussion over the mapping materials in one session, and then beginning the recorded interview in a later session after they had had time to think about their maps and to decide on which parts they would like to talk to us about.

We took a deliberately flexible approach in which we tried to work with storytellers to enable them to tell their stories in a way that was comfortable for them. This meant that some people attended a single interview, while others talked to us on as many as four separate occasions.

While we had some questions that we could ask during the interviews to help storytellers tell their stories, we did not have a rigid interview schedule. Instead we discussed with them what we would ask in the interviews before they began, and together agreed a strategy about how we would go forward. It had been our plan to try to co-produce interview questions with storytellers, but most found this idea difficult and preferred that we ask questions that were responsive to the story they were telling in the moment. We audio-recorded and transcribed all the stories.

When interviewing storytellers with caring responsibilities, we did not go through a lengthy mapping process as many of these storytellers had limited time available for the study.

WHY GET INVOLVED?

Dolly’s perspective

“the first thing that attracted me was my own experience of being in the psychiatric hospital. People were making decisions for me and talking about me. Nobody was actually asking me, as if I didn’t really exist. I felt like I was just a piece of merchandise.

They were listening more to my family than me and making decisions based on other people’s version of events. I think it’s really helpful for people to come in and talk about what they need to talk about.”
MAKING SENSE OF THE STORIES

When we began trying to make sense of the stories, one thing became clear quite quickly. Storytellers did not tell us their stories in neat, linear ways. Instead their stories often moved back and forwards in time, as they thought more carefully about different themes and events in their lives.

When we as a research team came together, we realised that carrying out a traditional thematic analysis alone would mean chopping up these stories into themes, which risked truncating them and losing the essence of storytelling and the oral history approach.

We did not want to lose the sense of the narratives and possibly, the important message contained within the whole story. However, we were also aware of patterns emerging across the stories of different storytellers and wanted to ensure that we did not lose these.

For this reason, we took a slightly unconventional, four stage approach to understanding these narratives.

1. STORIES AND PICTURES: MAKING COLLAGES

At the beginning of our analysis process, we found the richness of the stories we had heard overwhelming and, in some ways, difficult to make sense of. We decided that attempting to use a systematic approach to the data would be unproductive. Instead we used a creative, more intuitive approach.

We brought flipchart paper, pens, scissors, glue and magazines into the analysis meeting and began to make collages. We cut out images from the magazines and arranged them on the paper, sometimes talking about our choices and sometimes doing it in silence. After some rearrangement, we glued the images down. We made some notes by the images to capture what we were thinking about when we placed them together. We allowed ourselves to be led creatively by the aspects of the stories that spoke most powerfully to us.

Over a number of sessions, we created 7 collages on themes such as home and housing, relationships, emotions, medication and trying to access services. These collages enabled us to pinpoint some of the most important messages in the data, which we then incorporated in later stages of our analysis.
THE BENEFITS OF WORKING CREATIVELY

Rose’s reflection

Using collage in this way is probably not a traditional ‘academic’ approach to working with qualitative data. Whilst I have ‘academic’ training and over 10 years of experience in using traditional research methods, I probably do not comfortably fit within the ‘academic researcher’ box. I have been making things and pictures since I was very young.

It felt very natural to me when I began working on the stories with Dolly, Gary and Alison, who are also creative people, to try to make pictures about our data. The first time we tried this approach I remember that all four of us, for different reasons, were feeling quite flat and tired. Faced with the richness of the different stories, we found it difficult to digest and verbalise everything that was there.

When we began working together visually it was like we switched to a different part of our brains and began to work together very fluidly to unlock the stories and their meaning. I noticed that we worked very quietly together and there was little discussion while we were making the collages.

Each of us were drawn to different things. I tended to favour images, while for Gary, it was headlines or phrases. Dolly produced a ‘found’ poem from words in the magazines. Alison at times preferred to draw rather than to use images from magazines.

Once the collages were made, they were a great focus for the discussions that followed, both around what we had captured and also what we may have missed.
2. UNDERSTANDING CORE NARRATIVES

At the same time as working together on the collages, Dolly, Gary and Alison were also conducting a mini narrative analysis in which they looked at each story to identify the core ‘genre’ and the key ‘emotional tone’ of the stories.

Alison created a proforma and this helped us to identify the ways in which the narratives felt and sounded, as well as the core themes running through them.

3. DECIDING ON THEMES

After we had completed the collages, we worked together to decide which themes we should write about in our report. A theme was an important thread in the stories of some or all of our storytellers.

In total, we identified 10 themes. Examples include shared experiences like difficult early life events, difficult relationships, insecure housing or homelessness, and loneliness or isolation. We then wrote short sections about these themes. Each of us took the lead in writing half a page on a small number of themes.

We then circulated our writing and commented on each other’s work. Alison also wrote some sections in which she tried to capture a single story from one storyteller. We then brought these together and Rose edited all the sections together to create a single document.
4. THEMES AS STORIES

When we read our first draft, we found that by presenting the narratives as themes we had gone too far in the direction of ‘chopping up the stories’. This meant that when we used quotes from the interviews, they were no longer connected to the whole story and their power was lost.

We showed some of these sections to our steering group and they also felt that by chopping up the narratives to create themes, we had lost the essence of the stories. At this point we came back together as a research team and talked about how we could write our account in a way that invited readers to gain a better sense of each person’s story, while highlighting important themes and issues arising across the data. We decided to write about just one or two of the stories to illustrate each theme, in this way retaining whole stories within the context of a theme.

Once we had done this, we then went back through the narratives and tried to ‘cross reference’ all the different stories so that we could bring attention to some of the patterns that ran across some or all.

We hope we have achieved a successful balance with this approach; we certainly took time and care to work on it together. As a result, this account is a collective effort between all of the team members.